

The Michigan FAS Web



*"When spider webs unite they can tie up a lion."
~African Proverb~*

Asking the Hard Questions

by Carol Cole, FASAware Project Coordinator

I first learned the truth about FAS while attending a conference in Washtenaw County with national level speakers. As a professional, I wanted to know more about syndromes effecting families "at risk." It was at that conference that I began to see the "red flags" in my own 2 year old adopted son. At eight, my son is my best teacher as I seek to lead the Wayne County FAS Advisory Board.

The Wayne County project is known as FASAware. It's purpose is to reach out to families and professionals with the important FAS prevention and intervention message. In this third year of our project, we are seeking to answer some of the difficult questions we encountered in the first two years.

- *Has the training we have done so far been effective in reaching families for diagnosis and support services?*

The first two year's education and training efforts have been aimed primarily at mental health therapists and school personnel. The trainings were provided in settings that brought people from a variety of schools and agencies together to learn about FAS. Trainees reported that it was difficult to create change in their organizations because most of their colleagues had not been trained. Now we focus on going into individual schools and agencies and bringing the FAS message to the entire staff. As a result of this approach, several diagnostic inquiries have been made.

- *Why aren't Wayne County's diagnostic referral rates higher?*

Wayne County has over 50% of Michigan's foster care population. Is it unreasonable to assume that over 50% of the state's "alcohol exposed" population resides in Wayne County as well? In an ongoing effort to answer this question, the FASAware project has turned it's attention to reaching its large foster/

adoption population. Each of the County's 22 foster/adoption agencies has been contacted and trainings for both foster parents and staff have been scheduled.

- *Is FASAware visible and available to all of Wayne County's large and populous area?*

The FASAware brochure, which details local and statewide services, also includes our statewide toll free help line number. This graphic tool continues to be an effective way to reach large numbers. It is currently distributed at trainings and in local support service agencies through Advisory Board members. We seek to continually expand our members and contacts for distribution.

- *Have we been effective in reaching out to those most at risk with a strong prevention message?*

In the second year of our project, we began training teens and guiding them in getting prevention messages out to their peers. This has been very productive. So, we are working to continue facilitating such trainings and to distribute our prevention materials.

- *Do professionals and families have access to local resource materials for aid in prevention and intervention of FAS?*

We now have many excellent resources available from the library housed in The Guidance Center in Southgate. They currently stock over 34 FAS book titles, 20 FAS videos (some with curriculum guides), resource packets, and a variety of brochures. Anyone in the state can check out the books and videos. We plan to continue including the newest resources, as they become available.

*For more information, contact Carol Cole at
FASAware@comcast.net or call toll free (866) 484-4723.*

Proud to be Me

Joy is 13 years old. Petite and frail of frame, but there is no frailty of voice as she addresses her adult audience. She speaks clearly and confidently. Her audience is spell-bound. She speaks for 15 minutes to a group of parents who have come to learn about FAS. When she is done, a spontaneous, enthusiastic round of applause follows. Joy has been diagnosed with full Fetal Alcohol Syndrome. She wants to be an adoption therapist when she grows up. Observing her walking around after her speech, talking with parents and giving them ideas about how to help their kids, it is not hard to believe she will achieve her goal.

Joy's own parents, in attendance at the training, say that they are impressed with the way Joy is "blossoming" lately. Parenting Joy has not always been easy. The Williams' struggled for many years, trying to reason with Joy and to understand her behaviors. *"I would have done things differently (if I had been taught about FAS). There is no way I would have treated her the way I did,"* relates Mrs. Williams. *"That hurts me deeply. Now that I know (about FAS), she is blossoming. Now that I know, I am a much better parent. She is a much better child."*

Joy is the foster/adoptive child of Jack and Larita Williams. Joy came to them when she was just four weeks old. *"The doctors at the hospital said 'She is an FAS baby.' She had the shakes for two weeks. Nobody ever said it was life-long brain damage."* It was only recently that Jack and Larita learned about what having FAS really means. When therapy was not helping Joy with her be-

havioral issues, the Williams' did not give up. A friend recommended Spaulding for Children in Southfield. Cindy Nelson-Pouget, on FASAware's Advisory Board, started working with Joy. She invited Jack and Larita to attend an FAS training at the agency. The Williams found the training enlightening. *"Now I encourage every parent... birth, foster, and adoptive, to go to classes and*

find out what FAS means and what to do." says Mrs. Williams.

The Williams' were referred to Washtenaw County's FAS Diagnostic Center. *"When we got the diagnosis, we sat her down and told her. We did not hide anything. She has to deal with it,"* Mrs. Williams relates. *"Now I have to be a different parent. I have to be patient. That child wants to be good. Joy is loving. She opens her heart. She wants to help people. She is small, but she is going to be heard. She is a wonderful person."*

Joy attends Alanzo Bates Academy for the Gifted and Talented in Detroit. She started having tutors in 4th

grade. Her most difficult subject is math. As she tells her audience, she wanted to get good grades, but she also wanted to be liked by her friends. She wasn't studying as much as she needed to. As Joy told her audience: *"Finally, after my grades hit rock bottom, my parents had to sit me down and explain again this condition that I have and that I should not let it control me. After several sessions with Cindy and lectures and role play with my parents, I was able to see how my behavior affected my*

Me

I may be small, but I am strong.

My voice may squeak, but I'm heard when I speak.

Sure, I don't have a cellphone, but I still communicate.

Don't look down on me just because I don't have a "mate."

Why judge me by my size or type of shoe?

No matter what you say I can't always do what you do.

Don't turn up your nose and cast me down

Don't frown at me when I come around.

Some of you are cold, evil, hard yet I try to be warm,
nice and soft.

When you throw insults you throw where they hurt the most.

Going straight thru the heart, hard silver bullets

That tear me apart.

What I'm not good enough because I don't shop at K-mart?!

I want to stand up, to be strong and smart.

But when I do, like those silver bullets you rip,

You shred me apart.

No matter what I wear, I'm ugly in your eyes.

And because of this I know you'll recognize

That I'm strong, smart, and confident.

You can't always have your cup of tea.

Realize that there's only 1 person I can be.

If you haven't figured it out, that person is ME.

by Joy Williams

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grades. Role-playing helped me a great deal on how to problem solve. ... With Cindy, I learned to find acceptance. She helped me control the feelings and emotions that were kicking around inside. So I set my priorities straight and thought about my goals. I am very proud to say that as of today I am getting a "B+" (in math). Thank you mom and dad and Cindy from Spaulding."

Joy tells her audience, *"Now that I understand FAS, my life is a little easier. Now when my close friends ask, I can explain my condition. Understanding the effects of FAS helps me control or stop my behavior before it goes too far."*

In their efforts to support Joy in attaining her goals, the Williams are seeking ongoing support. They would like

to see Joy be able to meet with other children with FAS. *"I would like her to be able to talk over things that are going on inside her and be able to share the frustration."* They are concerned about the vulnerability associated with the need for peer acceptance. They also seek ongoing support for her education, as they see a need to have Joy continue the tutoring that has helped her so much.

Joy's public speaking ability is not her only talent. Joy's poetic gifts are also blossoming. The poem "ME," which she recited to her audience, provides meaningful insight into the struggles of a teen who is "different." It also depicts the resiliency of a young lady who, along with her parents and counselors, is meeting the challenge of daily life with FAS.

Journal of FAS International

A very exciting new resource is now available online. It is a new peer review journal dedicated to all aspects of Fetal Alcohol Spectrum Disorder (FASD). The Motherisk Program at The Hospital for Sick Children in Toronto is the Journal's publisher. The Motherisk Program was created in 1985 to provide evidence-based information and guidance about the safety or risk to the developing fetus or infant, of maternal exposure to drugs, chemicals, diseases, radiation and environmental agents. In 2003, this group launched the Journal of FAS International (J FAS Int) in order to advance the search for new knowledge and solutions related to alcohol use in pregnancy.

Motherisk was aware that in order to find research on FASD individuals had to search in numerous journals focusing on pediatrics, alcohol-related morbidity, and psychology -- just to name a few. When they decided to establish the first scientific, peer review journal for FASD, they made two critical choices:

- The journal will be web-based to allow unlimited access to clinicians, researchers, teachers, individuals affected by FASD (including parents, partners, siblings), program providers, community leaders and the public at large.
- The journal will be a one-stop shop. That is, in addition to publishing original research submitted to J FAS Int, the Editorial Board will select significant papers published elsewhere in the peer review literature, and report their findings. They will offer critical appraisal of their content and quality. This feature is included in the Scientific News section.

The inaugural volume of J FAS Int features an original paper from Dr. Paul Lemoine of Nantes, France. Dr. Lemoine was the first physician to publish evidence of Fetal Alcohol Syndrome. The article highlights Dr. Lemoine's personal story of his pursuit of the syndrome, and his follow-up of these original cases into adulthood. Other articles include critical reviews of research on:

- ◆ A genetic trait that may contribute to FAS
- ◆ The association of maternal alcohol use and SIDS
- ◆ Analysis of obstetric textbooks messages about alcohol use in pregnancy

The Journal also provides information about conferences and upcoming events. To access this journal, go to <http://www.motherisk.org/JFAS/>

Our FAScinating Journey: Keys to Brain Potential Along the Path of Prenatal Brain Injury

Our FAScinating Journey was written from a parent's perspective. In the book, which retails for \$39.95, Jodee Kulp shares experiences to help families raising children affected by prenatal alcohol exposure to become strong and united. On your journey through the book's pages you will:

- ♦ Discover creative approaches in reaching and loving children with attachment issues.
- ♦ Understand how alcohol affects the growing brains of children.
- ♦ Become familiar with brain terminology.
- ♦ Uncover ideas to help a child nutritionally.
- ♦ Wade through school and behavior issues with tears, laughter and strategies you may not have tried.
- ♦ Meet professionals who have helped the Kulp family help Liz grow.
- ♦ Smile as you get to know Liz, a very real teen who is determined to be the best she can be in spite of FASD.

Truth & Consequences of Fetal Alcohol Syndrome

The New Jersey Fetal Alcohol Syndrome Task Force is sponsoring the "Truth & Consequences of Fetal Alcohol Syndrome" conference on October 27—28, 2003. The conference will take place in Atlantic City, NJ and will feature:

- ♦ Jose Cordero, Assistant Surgeon General
- ♦ Ed Riley, National FAS Task Force Chair
- ♦ Kathleen Mitchell, National Organization on Fetal Alcohol Syndrome

Workshops will focus on:

- Research
- Education
- Family issues

Brochures are available on-line at <http://www.state.nj.us/humanservices/OPMRDD/ofp.html>

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